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Journal article

Implementing creative methods in baby loss research: Exploring stillbirth bereaved parents' journeys through collage

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Abstract

Grieving the loss of a baby may feel excruciatingly painful for parents. The rate of stillbirth in the United Kingdom is approximately 8 babies per day. However, the rate of stillbirth disproportionally affects BAME (Black, Asian, and Minority Ethnic). This paper explores an ongoing doctoral project which incorporates collage-making as a creative method to explore how BAME stillbirth bereaved parents access bereavement support. Creative methods may generate findings that can better reach public audiences to spark transformational change. Collage is a visual interpretive tool that is generally accessible to the public, and a straightforward art form. Collages are often created by selecting images from magazines or newspapers or textured paper mediums, where the participants cut or alters the images and arranges and attaches them to mediums such as cardboard or paper. Incorporating collage in research can serve as a useful method when engaging with participants who are perhaps not comfortable communicating their thoughts about sensitive subjects. In addition to using collage as a creative research method, this study also features collage as a reflexive tool. Collage is an efficient tool for uncovering what is not said out loud about grief, but which is very much present within a grieving person. Breaking the silence and sharing the loss of a child through creative methods enhances the understanding of the experience of perinatal loss and provides a voice to those who would otherwise remain unheard.

Introduction

Grieving the loss of a loved one is a powerful experience. At times, bereaved people may feel as if the words are literally taken away from them. Contrary to the assumption that loss and mourning a loved one can only bring about sadness and pain, creativity can serve as an outlet for those who seek to express their grief in a compelling and meaningful way (Brennan, 2015). This is especially true for parents who lose a child to stillbirth which is often considered a 'hidden loss' (Scott, 2011). After waiting for months for the arrival of a new life and new addition to the family, their journey comes to an abrupt halt that ends with heartbreak and the loss of a future with their child. Stillbirth conflicts with the 'natural order' of life and loss (Flenady et al., 2014), which may amplify parents' emotional pain and grief. Grieving the loss of a life that has yet to be lived in the world seems instinctively unjust. While measures have been put in place to reduce the number of stillbirths per year (Silver, 2019; Smith, 2015; Vais & Kean, 2015), the UK still currently has a rate of 1 in every 250 pregnancies which end in stillbirth; this is approximately 8 babies per day (Tommy's, 2020). Within the BAME (Black, Asian and Minority Ethnic) communities, these figures are even higher with women 1.5 to 2 times more likely to experience a stillbirth than white women due to socio-economic circumstances and deprivation amongst this group (Gardosi, 2013; Muglu et al., 2019; Ravelli et al., 2011).

It is important to note the stillbirth rate in BAME families when compared to white British families, because of the noticeable disparity of participation in research from these communities (Brown et al., 2014; Jutla & Raghavan, 2017). There is a paucity of evidence in terms of the factors affecting BAME bereaved parents' participation in stillbirth research, however there are several factors which might influence this, including inadequate recruitment strategies from researchers, as well as poor historical practices which have negatively impacted on the community's sense of trust in research. For example, the Tuskegee Syphilis Study (1932-1972), where researchers investigated the effects of syphilis on 400 men from a poor black community (CDC, 2020). In this research study, medical treatment was deliberately withheld, to examine the course of the untreated disease.

This lack of participation in research has been recognised more recently at a national level and as a result NHS (National Health Service) England has launched the Expert Research Centre on Health Inequalities which will explore specifically the challenges faced by individuals in BAME communities (NHS England, 2020). This article documents a segment

of an ongoing mixed-methods *Qual-qual* doctoral study which features a core qualitative component and two smaller qualitative supplementary components. The aim of the study will be to explore how stillbirth bereaved parents from different ethnic communities' access bereavement support.

Using collage to increase BAME community representation in research

Across the UK stillbirth occurs in all ethnic communities, but disproportionally affects BAME families (Esegbona-Adeigne & Olayiwola, 2020; Garcia et al., 2015; Penn et al., 2014). There have been long-standing variations in health outcomes in different ethnic communities (Bhopal, 2014), which has led to evidence suggesting that people from BAME communities are under-represented in UK health research (Smart & Harrison, 2016). It is recognised within health and wellbeing research that BAME groups are underrepresented in services compared to white populations (Jutlla & Raghavan, 2017). In a systematic review of BAME involvement in health and social care research, Dawson et al., (2018) found that there was a significant gap in BAME participation in health and social care studies. Often there is only a brief discussion within the studies' limitation sections addressing the lack of representation from BAME communities (Cacciatore et al., 2009; Gold et al., 2016; Pollock et al., 2020). Moreover, despite the evidence which demonstrates the higher risks and rates of pregnancy loss within BAME communities compared to white British families (Knight et al., 2015), there is limited published research on how BAME families in the UK choose to access stillbirth bereavement support. The lack of representation within stillbirth research literature translates to the perpetuation of continued poorer health outcomes for BAME communities (Memon et al., 2016). This study therefore aims to contribute to the diversity of the current literature on stillbirth bereaved parents by specifically focusing on the experiences of BAME stillbirth bereaved parents.

Socio-cultural barriers may be a challenge for some people from BAME communities participating in research (Harrison & Smart, 2016; Jutlla & Raghavan, 2017). There may be issues with accessing health care and health inequalities; modesty concerns associated with culture and religion; and linguistic and cultural barriers (Jutlla & Raghavan, 2017). Discussing pregnancy loss has become more normalised in recent years, however speaking of the baby's death is still proscribed in some cultures, leaving many parents in a shroud of silence and unable to express the reality of their immeasurable loss (Jonas-Simpson & McMahon, 2005). Waheed et al.,(2015) assert that potential participants might be discouraged from participating by family members who fear there may be stigma for the family or the broader community. When stigma

is attached to a condition, this may generate a considerable barrier to participation (Jutlla & Raghavan, 2017). As stillbirth is a concealed loss for many families, stigma of disclosing sensitive information may be a barrier which prevents participation in research studies (Budd et al., 2018).

Arts-based research may be a way to better engage with communities that do not often participate in research by challenging the limitations of traditional scientific research (Clover, 2011; Stiell et al., 2006). It captures data in a non-verbal manner which can activate different sensory expressions than can verbal communication alone (Henry & Verica, 2015). Collage is one arts-based activity that encourages people to participate in research without needing creative skills or extensive language (Stiell et al., 2006). Employing art can facilitate communication between different cultures and connect people from different backgrounds (Dewhurst, 2018). Including arts methods within research may be an attempt to break down barriers of privilege and power that exists between researcher and participant (Sinha & Hickman, 2016) which is important when working with marginalised populations. A more interactive research process emphasises social issues such as stillbirth bereavement amongst BAME communities that can draw attention from academic and public audiences and bring about transformational change (Foster, 2016).

Grief and bereavement research

Within the health community, there has been a growing interest in the use of visual methods from qualitative approaches in the social sciences (Bell, 2010). In mental health research, the literature suggests that implementing creative modalities in therapy can help “counsellors access a range of interventions to meet the multifaceted nature of loss” (Buser et al., 2015, pp.174). Creative modalities include, but are not limited to drawing, drama, music creation, painting, sound exercises, dance, and sculpture (Webb, 2003). It is important to note that each modality has its own purpose and aims within research (Buckingham, 2009). Through implementing creative modalities in therapy, service users who have difficulty verbalising grief can ‘give voice’ to their emotions (Edgar-Bailey & Kress, 2010). This can be beneficial for bereaved parents who often feel isolated and unable to openly speak about the loss of their child (Flenady et al., 2014).

When creative modalities from grief therapy are employed in qualitative research, researchers can adapt their methods to bring creativity to the social sciences. The use of visual methods has been applied across different disciplines, including psychology, psychiatry,

sociology, anthropology, and education; and are utilised when working with children and young adults (Buckingham, 2009; McNiff, 2011). Within my own research, creative methodologies will be utilised to present sensitive data through a more innovative approach coupled with the semi-structured interview, a well-established traditional method. Presenting data through visual methods will enrich this study by better capturing the participants' personal experiences (Halcomb, 2016). Nevertheless, no matter what methods are utilised in a project, implementing creativity can encourage the researcher to process data in a multifaceted manner (Buckingham, 2009).

My doctoral project will be utilising collage as a creative method to explore stillbirth bereavement in BAME communities which is an under-researched area of the maternity services (Budd et al., 2018) and which will as a result generate an original contribution to the stillbirth literature. Collages are visual interpretive tools that can bring experiential ways of understanding to research approaches (Butler-Kisber & Poldma, 2010). As arts-based research increases and develops, interest in collage has grown in qualitative disciplines as it enables the researcher to "work in a non-linear and intuitive way" (Butler-Kisber & Poldma, 2010, p.3). This is important because it facilitates an enriched understanding of the data being collected. Collages are often created by selecting images from magazines or newspapers or textured paper mediums, where the participants cut or alters the images and arranges and attaches them to mediums such as cardboard or paper. Painting and drawing are also techniques that may be included in a collage.

Here, Washington and Moxley (2008) assert that arts-based methods borrowed from the humanities can portray lived experiences of participants that other forms of social science research inquiry cannot. This is because arts-based methods illustrate and illuminate an individual's story in terms of how that one experience can represent the whole scope of a social issue (Feen-Calligan et al., 2009). As an art form, collage is generally accessible to the public, as the art materials needed to create a collage (glue, scissors, magazine, and newspaper images) are widely available (Chilton & Scotti, 2014). It is a practical modality that can be implemented in a variety of settings, from ongoing small groups to a one-time facilitated exercise (Strouse, 2014). This method enhances the research process (Vaikla-Poldma & White, 2003), and generates further personified and clear data (Butler-Kisber, 2010). Collage is a less intimidating self-expression process compared to drawing and painting (Chilton & Scotti 2014); where clear instructions are provided by the researcher so that the activity is structured, and yet has enough flexibility to ensure that the final product is as unique as the creator. This method is not

complicated to implement and can be repeated by others which makes it a reliable research method (McNiff, 2011). Implementing collage can help the researcher and the reader better understand the data together (Hunter et al., 2002). Additionally, using a visual item can help the researcher make connections that might otherwise go unnoticed (Butler-Kisber, 2008).

In the context of implementing creative methods, there may be psychological, cultural, and environmental structural barriers (Ross, 1981) that may inhibit the creative process. In a systematic review Woodall et al., (2010), reviewing BAME communities' participation in mental health research, found that fear and distrust were consistent barriers that communities identified as a reason for not participating in research. However, the systematic review concluded that providing clear and transparent guidance on what was expected of participants and the benefits of participating in research may reduce anxieties (Woodall et al., 2010). If BAME communities are not accustomed to participating in research studies, asking underrepresented communities to create a piece of art for research purposes may reduce the stigma of participating in research. Using creative research methods can facilitate research participation and make it easier for participants to fully express themselves (Kramer-Roy, 2015). A major advantage of using collage in research is that it enables the participant to be in control in terms of the way they want to share their story; making decisions about what images to use to represent their experience and choosing what they reveal (Vacchelli, 2017). Using creative methods is therefore an appropriate approach for this research study as it will enable the collection of experiential data which explores the sensitive nature of disclosing loss and the journey to seek out bereavement support. Creative methods can generate findings which can reach public audiences and prompt people to act against health inequalities such as baby loss (Washington & Moxley, 2008). Therefore, it is envisaged that this project will serve as a catalyst for bereaved parents to use the process of creating a collage about their grief journeys. This will facilitate transformative discussions with third sector and health organisations about how to better serve these communities in their time of loss.

Participant recruitment and inclusion

In this study, participants will be people who consider themselves to belong to a minority ethnic group. The term 'minority ethnic' is appropriate in the UK to describe people of non-white descent (Institute of Race Relations, 2019). However, minority ethnic is also used to include people who are white, but of non-British descent; most commonly including populations from Eastern Europe and Traveller communities (Devon County Council, 2019). Parents who match

the study's inclusion criteria will be those who have experienced the loss of a stillborn. This is defined as a baby born dead at 24 weeks or further into the pregnancy (NHS, 2018). Participants will be those people who have participated in befriender programmes or peer support groups. 'Befriending' is an emotional supportive relationship which is commonly offered by third party sectors, such as charities, for individuals with distressing physical and/or mental conditions (Siette, Cassidy & Priebe, 2017). Befriending opportunities serve as an alternative to staff-delivered care (Siette, Cassidy & Priebe, 2017). Volunteers provide one-to-one companionship and emotional support on a regular basis in place of professionally delivered support. In this study participants will also be at least of 18 years of age and will have lost a child to stillbirth within the past ten years. Participants must be able to read and speak English at a proficient level to understand and provide their informed consent, and to understand the questions being asked during the semi-structured interview.

BAME stillbirth bereaved parents will be invited to participate in the study through charity collaboration and through snowball sampling (Noy, 2008). It is important to note that data has not been collected yet due to complications stemming from the COVID-19 pandemic. However, I intend to recruit 15 participants. Participants will primarily be recruited from four baby loss charities who are promoting my study in England. Recruitment efforts will be publicised by communication staff through the mediums of newsletters, social media accounts (primarily Twitter and Facebook), and the flyers I have created. Furthermore, participants may also hear about the study through other channels such as midwives, other healthcare professionals, and faith practitioners who I have met. This project was given ethical approval by Faculty of Health and Wellbeing Research Ethics Committee at my university.

Implementing collage-making in research

The purpose of incorporating the collage-making activity is to enhance the data collection procedure in anticipation of the generation of additional rich data that may not be produced through semi-structure interviews alone. Collage serves as a rich supplementary secondary data source because it produces qualitative data while working with sensitive topics (Vacchelli, 2018). I will invite participants to create collages where they will reflect on their experiences of seeking bereavement support for their loss. I will be following Butler-Kisber's (2010) approach, which supports the use of collage as an arts-informed option for qualitative research as it allows the researcher to work in a more intuitive manner, by increasing the representation of participants' realities, and so challenge traditional research methods that often prefer linear

thinking (Butler-Kisber, 2008). Over the course of a year, I have collected dozens of magazines which span across several interest genres. I will take the materials to the semi-structured interview location for participants to ensure everyone has an opportunity to contribute if they are unable to supply their own materials. However, if parents would like to use their own items, they may do so or in conjunction with the materials I have provided. This will further reduce the researcher's subjective influence in the research as participants will have different experiences and will relate to the varied materials being used.

Following the completion of a semi-structured interview, participants will be invited to construct a collage. The rationale for asking parents to participate in the collage making after the completion of the semi-structured interview is that it may spark further dialogue and insight which may supplement the interview data. Implementing the collage-making activity after the semi-structured interview which discusses a sensitive topic, allows for rapport and trust to be developed and enhanced between the researcher and participant(s) as it is an engaging activity for both. Furthermore, integrating the collage making activity after the semi-structured interview further facilitates the conversation about their experiences of seeking bereavement support.

It is envisaged that the collage making activity will take up to sixty minutes of the participants' time in a place of their choosing. I will be present during the activity and will provide verbal instructions on how to create a collage and an example of one I have created will be provided to inform and inspire participants. Instructions will be simple to ensure participants have the freedom to create a collage that captures their experiences. Participants will be asked to find pictures and words from the materials provided that represent their experiences of seeking out bereavement support for the loss of their child. The basic skills of cutting, applying glue, and sticking images to paper are often developed early in life. Collage can easily be carried out by anyone and can become a part of any art novice's repertoire. Participants can decline to take part in the activity; equally they will be given the opportunity and be encouraged to return at a later date to make a collage if they change their mind. To protect participants' identities, I will anonymise the collages, and will assign each collage a number. Confidentiality will be maintained throughout the project and data stored in accordance with General Data Protection Regulations (GDPR), the Data Protection Act 2018 and University Research and Governance University Research and Governance regulations with regards to confidentiality.

Analysis of interview

I will be employing a semi-structured interview model, because it will be the most effective way to guide a highly sensitive and emotionally provoking conversation, and yet offer space for participants to speak candidly on other matters they might want to share (Morse & Niehaus, 2009).

To analyse the data, I plan to use Morse and Niehaus' (2009) approach to Grounded Theory (GT) it is useful when applied to an emerging area of research or when there are no other theories available that address the problem or represent the participants in the study (Bryant & Charmaz, 2007, Creswell, 2014).

Applying Morse and Niehaus' (2009) stance to this project, the interviews and collages will be analysed independently from one another. However, as the collages are a supplemental component of the research project, their purpose is to enhance the findings which arise from the semi-structured interview data. Combining both linear (semi-structured interviews) and non-linear (collage) research methods will enhance the research project as each method will illuminate the challenges bereaved parents face when seeking appropriate bereavement support.

Analysis of collage

Thematic analysis (TA) will be used to analyse the collages. Thematic Analysis is a convenient approach to use across disciplines as it is flexible in terms of the types of research questions and forms of qualitative data to which it can be applied (Clarke & Braun, 2014). For this doctoral project, TA will be used as a complementary method to analyse collages as it will create a better understanding of BAME stillbirth bereaved parents' journeys when accessing bereavement support through a thorough and reflective process. As an encompassing strategy, TA can be applied to both textual and visual data.

Collage as a medium within arts-based research is recommended because the actual process of creating a collage can serve as part of data collection (Chilton & Scotti, 2014). Collages most often portray images and words. It is expected that participants will want to discuss the themes that they notice in their work, which will guide my initial analysis. I will continue to analyse why participants (as a complete data set) chose specific imagery included in the piece and analyse the final product. I will code patterns of the images and words to identify how BAME stillbirth bereaved parents access bereavement support. When analysing

multiple collages, researchers can identify reoccurring visual themes that may provide insights that may escape rational thought processes when using traditional methods such as interviews (Jongeward, 2009).

Autoethnographic research using collage-making

McNiff (2011) suggests that for arts-based research such as collage-making to occur, both the researcher and the participants must be involved in some form of creative art. This form of research demands an increased level of engagement from the researcher but can produce insights about the research that might not otherwise be explored without a self-reflective component (Delamont, 2009). As a researcher, creating collages as a reflexive tool helps to maintain my connection to the research question and process (Chilton & Scotti, 2014). By completing the collage making activity as a researcher, I will be able to explore and challenge established ways of doing research and question established political, socially-just, and socially conscious norms (Ellis et al., 2011). The purpose of creating an autoethnographic component is to examine my own reflexivity through sharing my personal experience of grief while researching this topic and to examine my position as a white immigrant woman working with BAME communities. This supplementary collage making component will help me to explore my experience of seeking out the most appropriate support for me. This will inform the analysis of the data as I will be able to share the experience of searching for bereavement support for myself. Although my grief differs in nature and circumstances from participants' experiences of losing a child, using collage in this way is still valid as it will consider the navigation of bereavement support pathways in a country which is not my own.

Thus far, I have created two collages: one near the first anniversary of my mother's death in December 2019 (Figure 1) and one at the beginning of the COVID-19 outbreak in the UK (Figure 2). To create both collages, I used images and words from fashion magazines. The first collage (Figure 1) is centred around words and phrases as textual data that I felt was aligned with my own experience of grief. At the time, I found it difficult to find a lot of images that resonated with me. This collage also displays how difficult it is to be away from my family while trying to be a student. One can see this through images of the American flag, a picture of the United States, the short phrase 'family in America', and the school desk. In contrast, the second collage (Figure 2), is more balanced between images and text. I found images that applied to both the COVID-19 quarantine lockdown period and for Mothering Sunday. There is an image of a child and mother that resounded with me. I made sure it was mostly in focus

to showcase the importance of the image. This collage has the word ‘home’ with the Union Jack displayed within it. This word represents where I consider my chosen home to be despite there being tension between my life in the UK and my life in the US. Both collages are on pastel coloured paper that represents my mother’s favourite colours.

Collage has been a part of my educational upbringing since I was a little girl, meaning the process of creating one was innately familiar and straightforward. It is an easy craft to partake in, and unless one wants to incorporate another method such as drawing, no artistic skills are required. An important benefit of collage is that it can be a quick exercise to implement in a short period of time. In recent years, collages created by adults have been called ‘vision boards’ or ‘mood boards’, yet the substance of cutting and pasting remain the same methods to create either of these types of collages. Personally, the act of creating a collage is an intimate exercise which relates to the loss of my mother. Creativity came easily to her in multiple mediums. She would create collages as an art project for her own amusement. The act of creating my own collages was an enjoyable process because I knew she had found it to be a fun exercise. It serves as a fitting tribute to include her presence within a research project about grief.

Implementing collage as a reflexive component enables me to step into the shoes of the participants. It helps inform the actual process and procedures. For example, I have experienced the physical sensations of scanning magazines, cutting out images, and pasting them onto the paper. I can provide clear instructions because I know how to complete the exercise myself. It emphasised the need to have a diverse range of magazines and newspapers for people to find items that speak to them. Additionally, I know what it feels like emotionally to come across a striking image or word that speaks to my experience of being bereaved. It can feel poignant and bittersweet to find a fragment of a magazine page that speaks so loudly to oneself; making it an essential piece to include within the collage. Through both the physical and emotional application, I’m able to better facilitate the collage exercise since I have experience of creating and contributing pieces for my own portion of the research project.

The collages I have created serve as visual diaries of my evolving journey of my own grief and serve as a reflexivity tool. I was surprised by the depth and multiple meanings that emerged. It is difficult to predict what images or words will speak to a person when creating a collage. Sometimes, it can feel like a “stroke of luck”; being able to find several meaningful images or quotes in one magazine versus another one that does not speak at all to the creator. I

find this to be a benefit of the research method. By beginning the exercise without any preconceived intentions of finding a specific image, what is found seems to reflect more accurately unconscious thoughts and emotions. Building an intuitive collage does not necessarily make rational sense. The imagery one chooses to include within the final product can feel emotional and revealing; more so, than verbally speaking about loss. As it is a straightforward art activity, it does not appear to provoke anxiety trying to create a masterpiece. When the board is full, there can be a natural sense that the exercise is complete. It is a beneficial reflective method because it serves as a visual representation of a moment in time; an exercise that can be kept as a memento of that specific time-period. Collage can be an efficient tool for uncovering what is not said out loud about grief, but which is very much present within a grieving person.

Conclusion

It is essential to note that the experience of baby loss and grief is not easily understood nor shared. Although creative modalities have been implemented in the field of mental health predominately through grief therapy, research within grief and bereavement research incorporating creative methods is limited (Bulger, 2016; Willer et al., 2018). Creating collages for research provides participants a way to weave their story together through words and images, giving a multifaceted account to their experiences. Collage is a rational arts-based research method that is inexpensive and is an approachable medium for people from diverse cultures. Incorporating collage in research can serve as a useful method when engaging with participants who are perhaps not comfortable communicating their thoughts about sensitive subjects. Collage also serves as a useful tool to examine reflexivity. Creative methods such as arts-based scholarship enables the findings from the research to be more accessible as it can reach multiple audiences (Boydell et al., 2012). Like the arts, qualitative research has been viewed as an effective tool for conveying social phenomena where the representation of such experiences would otherwise be limited (Szto et al., 2005). Capturing the stories of bereaved stillborn parents from BAME backgrounds is essential as it will diversify the baby loss literature and serve as a vehicle for service providers to better help these communities. Breaking the silence and sharing the loss of a child through creative methods enhances the understanding of the experience of perinatal loss and provides a voice to those who would otherwise remain unheard.

